Consequences of stroke and aphasia according to the ICF domains: Views of Portuguese people with aphasia, family members and professionals

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Background: Addressing the long-term consequences of stroke is a top-ten research priority (Pollock, St George, Fenton, & Firkins, In Press), and understanding the views of different stakeholders is essential in designing appropriate patient-centred multidisciplinary rehabilitation.

Aims: This study reports on the perspectives of 38 individuals who live with or work with aphasia: people with aphasia (PWA), family members and friends (FM), and speech and language therapists (SLTs), about its consequences in the daily lives of people with aphasia.

Method & Resources: Fourteen PWA, 14 FM, and 10 SLTs participated in the study. All participants were interviewed about the consequences of stroke and aphasia. Small focus groups were used with some participants. In-depth semi-structured interviews were used with other participants. Interviews were carried out in groups or individually in order to accommodate severe aphasic impairments, or respondents with fewer years of education. Interviews were video or audio-recorded. Verbal and non-verbal communication was transcribed and analysed qualitatively using content analysis. Data was coded and mapped onto the ICF framework.

Outcomes & Results: All three groups reported consequences in *Body Functions and Body Structures*, primarily in *Mental Functions (Specific Mental Functions and Global Mental Functions) and Neuromusculoskeletal and Movement-Related Functions.* Within Specific *Mental Functions*, PWA emphasised *Expression of Oral Language*, whereas FM and SLTs emphasised *Emotional Functions.* Within *Global Mental Functions,* PWA and FM emphasised *Energy and Drive Functions* whereas SLTs emphasised *Temperament and Personality Functions.* Some consequences were shared between PWA and SLTs (*Sensory Functions and Pain, and Functions of the Digestive, Metabolic and Endocrine Systems*), whilst others were specific to SLTs alone (*Voice and Speech Functions, and Cardiovascular, Haematological, Immunological and Respiratory Systems*). All three groups reported consequences in Activities and Participation in *Major Life Areas*; *Community, Social and Civic Life*; *Interpersonal Interactions and Relationships*; *Communication; and Mobility*. Some consequences were shared by PWA and FM (*Domestic Life),* and others by FM and SLT (*Self Care*). Consequences in *General Tasks and Demands* were only described by SLTs and in *Learning and Applying Knowledge* by PWA. Both PWA and FM reported a general Loss of Autonomy.

Conclusions: PWA, FM and SLTs reported a considerable range of stroke and aphasia consequences in the daily life of those who live with it. They were concerned to different degrees with language, physical, and emotional changes, and impact on communication, mobility, self-care, relationships, leisure and work. Professionals' practices in Portugal need to be changed in order to consider these findings.

Keywords: aphasia; consequences; ICF; family members; clinicians.

INTRODUCTION

Background

Stroke is considered the third leading cause of death and permanent disability in developed countries (Direcção Geral de Saúde (DGS) – Portuguese "Central Health Agency" 2010). In Portugal, stroke is the first cause of death (DGS, 2008) and disability (DGS, 2010; Martins, 2006) and is therefore one of the most frequent diseases causing hospitalisation (Ferro & Pimentel, 2006). Aphasia is a common consequence of stroke, affecting one third of the stroke population (Darrigrand et al., 2011; Kelly, Brady, & Enderby, 2010), and has a significant onward impact on people's lives (Martin, Thompson, & Worrall, 2008). Addressing the long-term consequences of stroke is a top-ten research priority, and includes helping stroke survivors and their families cope with speech problems (Pollock et al., In Press).

Qualitative interview-led research of the 1990s revealed diverse consequences of aphasia and stroke. People reported obvious difficulties associated with impaired language, including effort in communicating, and difficulties with speaking, speaking in a group for a range of reasons, conversing, making oneself understood, writing and reading (Le Dorze & Brassard, 1995; Zemva, 1999). Stroke-related physical consequences also feature physical dependency, paralysis, fatigue, volatility, irritability, a life dominated by therapy, and difficulties with concentration (Le Dorze & Brassard, 1995; Parr, 1994; Zemva, 1999). Social consequences include restriction of social life, loss of or fewer contacts with friends, boredom and loneliness (Parr, 1994; Zemva, 1999). Emotional consequences include difficulty controlling emotions, a loss of confidence, and fear of another stroke (Le Dorze & Brassard, 1995; Parr, 1994; Zemva, 1999). Parr's (2007) later research with people with severe aphasia in domestic and care settings revealed a range of social and emotional consequences including isolation, boredom, depression, passivity, bewilderment, fear, anger, apathy, and hopelessness and a significant impact on identity and personhood, self-esteem, aspirations and dependence. More general consequences of a material nature have also been noted such as restriction of or loss of work, financial difficulties, drop in standards, housing hardships, inequitable access to services, and limited access to information and communication technology (Parr, 1994, 2007).

Whilst much of previous work has concentrated on specific communication, emotional, and cognitive sequelae, more recent research (Darrigrand et al., 2011; Grawburg, Howe, Worrall, & Scarinci, 2013; Mazaux et al., 2013; Natterlund, 2010) into the impact of aphasia reveals an emergent focus on activities and support. Interviews with 20 Swedish men and women with chronic expressive aphasia revealed substantial changes in everyday life activities, particularly leisure and work activities, and instrumental, informational and emotional support was needed to assist people with aphasia to improve daily life (Natterlund, 2010). Darrigrand et al. (2011) reported people with severe aphasia (N = 36) to be extremely limited in their communicative activities, with performance three times lower than people with moderate aphasia and four times lower than individuals without aphasia. A larger (N = 100) study (Mazaux et

al., 2013) undertaken by the same researchers with people with predominantly mild aphasia found similar self-reported difficulties, and additional limitations in engaging in conversation on complex themes or abstract topics or with strangers, using the phone for a meeting and communicating during social activities.

Consequences for partners, children, parents, siblings, friends, colleagues and the community where the person with aphasia lives have also been identified (Le Dorze & Brassard, 1995; Martin et al., 2008; Zemva, 1999). The difficulty of dealing with the problems accompanying aphasia with an increased stress related with the emotional and behavioural changes in the aphasic member and changes in social life, changes in communication and interpersonal relationships, heightened responsibilities and evidence of some stigmatisation are some of these reported consequences. The impact of aphasia on family members and close relatives has also recently been studied as *third-party functioning* and *third-party disability* (Grawburg et al., 2013). Grawburg et al. (2013) study of 20 family members' (including wife, husband, son, daughter, mother, father, brother, sister and granddaughter) functioning and disability in relation to their significant others' with aphasia health condition, framed respondents' views using the ICF domains. Analysis revealed five categories of positive aphasia related changes (functioning): *Mental Functions*; *Communication; Interpersonal Interactions and Relationships; Major Life Areas and Community, Social and Civic Life. It also showed* six categories of negative related changes (disability): *Mental Functions; Communication; Interpersonal Interactions and Relationships; Major Life Areas; Community, Social and Civic Life; Domestic Life*.

Differences in views

Understanding the views of different stakeholders is essential in designing appropriate patient-centred multidisciplinary rehabilitation. Research of some decades has shown that parties involved think differently. Lomas et al.'s (1987) work revealed that people with aphasia (PWA) focused on *specific, concrete* communicative situations (such as giving directions to a taxi driver, or finding a washroom in a public place), whilst clinicians (including rehabilitation physicians, nurses, speech and language therapists (SLTs), a neuropsychologist, and a social worker) focused on *generic* activities (such as giving simple instructions or following complex instructions). PWA emphasised social need situations (communication with others as an end in and of itself), whereas clinicians prioritised life skill situations (needed for daily living) (Lomas et al., 1987). Research exploring the consequences caused by aphasia illustrated that clinicians were focused on impact of aphasia on conversational ability or frustration experienced, whereas spouses were concerned with how other people reacted to the aphasic communicator (Oxenham, Sheard, & Adams, 1995). Le Dorze and Brassard's (1995) findings showed that both PWA and relatives agreed on the consequences arising from aphasia as changes in communication situations and interpersonal relationships, restricted activities, and stigmatisation. However, separately, they had different opinions. PWA were concerned about loss of autonomy. Relatives were concerned with increased responsibilities and the difficulties experienced adapting to behavioural changes or emotional reactions of PWA (Le Dorze & Brassard, 1995). Zemva (1999) also highlighted that PWA placed more value on their communication problems, while their relatives are more concerned with the problems accompanying aphasia, such as

the person's behavioural changes, ups and downs in mood, and changes in emotional reactions.

Differing views have also been noted in recent research into perspectives of quality of life (Cruice, Hill, Worrall, & Hickson, 2008) and what constitutes living successfully with chronic aphasia (Brown, Worrall, Davidson, & Howe, 2012), as well as aspects more specific to rehabilitation, namely desirable goals for therapy (Sherratt et al., 2011, pp. 325-326). Cruice et al. (2008) interviewed 30 PWA and 30 family members' and friends' about quality of life with aphasia. Their aim was to identify agreement or discrepancy between the two groups' views about this subject, and concluded that only about one third of family and friends raised the same issues as their aphasic partners. The research also revealed that many categories suggested by PWA as contributing to their quality of live (e.g., communication strengths, support from others, concerns about losing residual body functioning and negative impact of communication on people's life activities) were not identified by their proxies. A recent meta-analysis (Brown, Worrall, Davidson, & Howe, 2012) of three studies revealed that PWA, family members (FM) and SLTs agreed on many aspects that relate to living successfully with aphasia (Brown et al., 2012), however small differences in perspectives did emerge. PWA and FM emphasised verbal communication, whereas SLTs emphasised multimodal communication and strategy use; all three raised support but PWA and FM emphasised need to balance this with independence/autonomy (Brown et al., 2012). Worrall et al. (2009) explored and compared the goals for therapy of PWA, FM and their treating SLTs. While common communication goals were evident across all groups some divergences between them also arose. PWA highlighted the need of information, control and independence, dignity and respect, return to pre stroke life, social, leisure and work, altruistic and contribution to society and physical function and health as goals for therapy. SLTs valued the need of education, support, evaluation and considering personal factors when defining therapy, while FM considered the need of stimulation, the need of the person with aphasia being independent, handling emergencies, having social contact and a meaningful life, as well as a sense of survival. Differing views amongst different stakeholders are not surprising, and are likely due to the different experience of the condition (professional versus lived experience), different priorities, and different ways of managing and living with disability.

The WHO ICF Framework

In current clinical practice, SLTs are encouraged to take a holistic approach to intervention, and assess the impact of residual deficits on an individual's performance in daily tasks and participation in life situations, as well as consider socially relevant treatments (Ross & Wertz, 2005). This directive is facilitated by using the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001) which describes health and health related states from a biopsychosocial perspective (WHO, 2001). The ICF considers health related information in two distinct parts: Functioning and Disability (Body structures/ Body functions and Activities/ Participation) and Contextual factors (Environmental and Personal Factors). Body structures and functions component describes anatomic parts and physiologic functions, respectively and consists of eight chapters (WHO, 2001, p. 29). Body Functions component also consists of eight chapters (WHO, 2001, p. 29). The Activities and Participation component describes the

complete range of human functioning from both an individual and a societal perspective and is comprised of nine chapters (WHO, 2001, p. 30). The individual perspective is expressed through the concept of Activity defined as ‘‘the execution of a task or action by an individual’’ (WHO, 2001, p. 10). The societal perspective is expressed through the concept of Participation and is defined as the ‘‘involvement in a life situation’’ (WHO, 2001, p. 10). Contextual factors are comprised of five chapters (WHO, 2001, p. 30) and “represent the complete background of an individual's life and living” (WHO, 2001, p. 16), including: Environmental Factors and Personal Factors. Environmental Factors “make up the physical, social and attitudinal environment in which people live and conduct their lives” and are external to the individual (WHO, 2001, p. 16). Personal Factors are “the particular background of an individual’s life and living, and comprise features of the individual that are not part of a health condition or health states” (WHO, 2001, p. 17).

However, the ICF comprises more than 1400 categories, distributed along the referred domains, making it difficult to use in clinical context (Alguren, Lundgren-Nilsson, & Sunneragen, 2010; Grill & Stucki, 2011). In order to improve the clinical practicability of ICF in practice, ICF Core Sets, have been developed for specific health conditions (Cieza et al., 2004; Jácome, Marques, Gabriel, & Figueiredo, 2013). Both brief and comprehensive core sets have been devised for various conditions. Brief core set consists of a minimum number of concepts recommended for research purposes and comprehensive core set being advocated for clinical practice (Cieza et al., 2004).

The ICF is used frequently as a framework to structure research findings as well as to define therapy and its goals. Early research (Le Dorze & Brassard, 1995; Oxenham et al., 1995) used the conceptual precursor to the framework of ICF (at the time using the existing framework of the International Classification of Impairments, Disabilities and Handicaps - ICIDH) to broadly differentiate consequences of stroke and aphasia. Recent research more closely applies the domains and coding (Grawburg et al., 2013). Finally, the framework has also been used in validation studies of the comprehensive core set with stroke survivors (Alguren et al., 2010; Paanalahti, Lundgren-Nilsson, Arndt, & Sunnerhagen, 2013) demonstrating the relevance of these but also identifying areas where the comprehensive set could be reduced in places (Alguren et al., 2010).

Aim of the study

This study aims to explore and understand the perspectives of Portuguese PWA, FM and SLTs of the consequences of stroke and aphasia in their daily lives. We intentionally enquired holistically about the consequences of stroke as well as those of aphasia, as previous researchers have noted that participants (individuals with aphasia and significant others) often recount their experiences as a whole, that is they do not isolate the impact of aphasia from the impact of other consequences (Grawburg et al., 2013). This research is important in supporting a broader scope of practice, understanding the value of different stakeholders’ view, and in underpinning new developments in assessment tools (Matos, 2012; Matos, Jesus, Cruice, & Gomes, 2010a, 2010b).

METHOD

Study design

This study explored the perspectives of 38 individuals who live with or work with aphasia, incorporating the views of three stakeholder groups: 14 individuals with aphasia, 14 family members, and 10 speech and language therapists (see Participants section below for further information). All participants with aphasia were recruited and assessed by the first author at the Centro Hospitalar e Universitário de Coimbra (CHUC), Coimbra, Portugal. In order to obtain as much information as possible from participants a qualitative approach was deemed appropriate. Focus groups were used with some participants. In-depth semi-structured interviews were used with other participants. Interviews were carried out in groups or individually in order to accommodate severe aphasic impairments, or respondents with fewer years of education[1]. Interviews were video-recorded and transcribed verbatim was produced. The transcripts were analysed using content analysis, more specifically thematic analysis (Bardin, 1977; Berelson, 1971). Interviews with PWA and FM explored questions related with the impact of stroke and aphasia in their daily lives in terms of: disability and functionality; satisfaction level with social participation; changes they would like to introduce in their lives. A topic guide was used (see appendix 1). Focus group with SLTs explored questions such as: What are the consequences of stroke in the lives of those whom you work with? What are the consequences of aphasia in the lives of those whom you work with? What are the activities they actually do? What are the activities they usually refer as not doing anymore after stroke and aphasia? How do they participate in society? All interviews were conducted in European Portuguese (EP).

Participants

People with aphasia (PWA)

Twenty-three individuals with aphasia were contacted, but 7 were unable to participate because of health problems, time constraints, transport difficulties, or resolved aphasia. Initially, 16 participants with aphasia took part in this study. The following inclusion criteria were defined: over 25 years of age; native speakers of EP; having at least 3 months post onset following a stroke; living at home; aphasia diagnosis according to the Bateria de Avaliação da Afasia de Lisboa (BAAL: (Castro-Caldas, 1979; Damásio, 1973; Ferro, 1986); a reliable yes/no response (no less than 7 on the BAAL yes/no questions); no cognitive disturbance according to the language-modified Mini-Mental Status Examination (Pashek, 2008) Portuguese version (LMMSE: (Matos & Jesus, 2011) (no less than 22 in a total of 30); no hearing problems that interfered in the communication process, as reported by the person with aphasia; no depression according to the Centre for Epidemiologic Studies Depression Scale (CES-D: (Radloff, 1979) Portuguese version (Gonçalves & Fagulha, 2004) (values between 20 and 60 indicate depression). Participants completed the assessments, BAAL, LMMSE and

[1] This decision was made in consideration of the larger research study (Matos, 2012) wherein participants needed to comment on translated assessments of communication disability and participation, and were thought to respond more with individual support.

CES-D, with an experienced, qualified Speech and Language Therapist (first author). After assessment, 2 individuals were excluded because depressive symptoms were evident.

Fourteen individuals with aphasia (11 men; 3 women) participated in the study, and had a mean age of 65 years (range 41-80 years; SD = 11.2), and a mean 7 years of schooling (range 3-20 years; SD = 5.5) (see Table 1). Participants were on average 29 months post-stroke (range 3-89 months; SD = 27.7). Eight participants had a physical impairment but were ambulant. A range of aphasia profiles was noted: anomic (n=7); conduction (n=1); Broca's (n=1); transcortical sensory (n=1); transcortical motor (n=3); global (n=1). Eleven participants were retired, two were on sickness benefits, and one was working part-time. Participants scored within the normal range for cognitive functioning (mean LMMSE = 26.7; SD = 5.4; range 23-30) and similarly for emotional functioning/depression (mean CES-D = 9.0; SD = 5.3; range 2-20).

Family members and Friends (FM)

A family member was selected by each person with aphasia to participate in the study, and each was required to meet inclusion criteria: native speaker of EP; spend a minimum of 10 hours/week in direct contact with the person with aphasia; no history of neurological disease or other situation that affects the person's language and/or communication capacities; no cognitive disturbance according to the Mini-Mental Status Examination (Folstein, 1975) Portuguese version (Guerreiro, Silva, & Botelho, 1994) (no less than 22 in a total of 30); no depression according to the Centre for Epidemiologic Studies Depression Scale (CES-D: (Radloff, 1979) Portuguese version (Gonçalves & Fagulha, 2004). All FM met these criteria.

Fourteen family members and friends of people with aphasia (9 men; 5 women) participated in the study, and had a mean age of 57 years (range 33-70 years; SD = 12.1), and a mean 7.5 years of schooling (range 4-16 years; SD = 4.2) (see Table 2). Six had only attended primary school (4 years), five had between 4 and 11 years of schooling, and three had 12 or more years of schooling and education. Participants with aphasia selected the following to participate in the study: seven spouses; four children; two friends; one father. Eight were retired and six were working (two salesmen; two housekeeping or domestic; one seamstress; one factory worker). No hearing difficulties were reported, and 11 participants reported needing glasses for daily living. All participants scored within normal range for cognitive functioning (mean MMSE = 29.14; range 26-30; SD = 1.09), and emotional functioning/ depression (mean CES-D = 9.1; SD = 5.6; range 0-17).

Speech and Language Therapists (SLTs)

A total of 18 SLTs were contacted by phone and email, and 10 were available and interested in participating in the study. The inclusion criteria were: a qualified Speech and Language Therapist (SLT); at least one year of clinical experience with PWA; working in a hospital setting, rehabilitation centre or other healthcare provider, representing different geographic parts of Portugal.

The 10 SLTs comprised eight women and two men, with an average age of 34.9 years (range 25-52 years; SD = 9.3) (see Table 3). Seven participants had an undergraduate

degree and three a M.Sc. degree and their basic training took place between 1976 and 2004. They had an average 12.4 years' experience (range 2.6-31years; SD = 9.7) of intervention with PWA.

Five participants were working in a hospital setting, and two were both lecturers in Speech and Language Therapy courses and private practitioners. The remaining three participants were employed by the National Aphasia Association, a rehabilitation centre, and a health centre. The participants were geographically representative of the country: five SLTs worked in south of Portugal; three were from the north; the remaining two were from the centre of Portugal.

Procedure

Participants with mild to moderate aphasia (n = 7; BAAL severity scale > 3) were interviewed as a group. Participants with severe aphasia (n = 7; BAAL severity scale < 3) were interviewed individually, in a supported conversation manner, using a range of appropriate multi-modality total communication strategies as suggested by different authors in the literature (Aleligay, Worrall, & Rose, 2008; Davidson, Worrall, & Hickson, 2008; Luck & Rose, 2007). An aphasia-friendly topic guide was used. FM with good education levels (n = 6; $\geq$ 5 years schooling) were interviewed as a group. FM with low education levels (n = 8; $\leq$ 4 years schooling) were interviewed individually. Same topic guide focused on the consequences of stroke and aphasia in their own lives, as well as their aphasic individual was used. Interviews with PWA and FM addressed the consequences of stroke and aphasia on functioning, activity and participation, and also explored barriers and facilitators, including strategies to deal with barriers. PWA considered themselves only; FM considered both themselves and their aphasic partner.

In order to clarify and standardise the terminology used in this work, an initial presentation by the first author of this paper was made about the ICF concepts and terminology. The SLTs participated in small groups of either three or four participants, facilitated by the lead researcher (first author) to discuss their views of the consequences of stroke and aphasia on daily life of PWA. Following this discussion, each group collectively recorded their thoughts and opinions about the consequences of stroke, consequences of aphasia, activities, participation, barriers, and facilitators, as well as their own demographic and work history information. This method of data collection was used with this stakeholder group, as the SLTs were contributing to several activities as part of the larger research study (Matos, 2012), and data was collected in the same day.

This study was conducted with ethical approval from the relevant research ethics committees. Aphasia-friendly accessible versions of the information sheet and consent form for PWA were developed following internationally recognised recommendations (Aleligay et al., 2008; Davidson et al., 2008; Luck & Rose, 2007).

Data analysis

Group interviews and individual interviews with participants with aphasia were video-recorded using a Sony DCR-DVD306 camcorder to allow verbatim transcription for analysis and interpretation of participants' responses. The 8 individual interviews with

family members were recorded using an Olympus WS-110 digital voice recorder. Videos of the group and individual interviews were transcribed by a newly qualified Portuguese SLT. The use of multi-modality total communication strategies by PWA was also transcribed. PWA and FM responses were analysed qualitatively using content analysis, more specifically thematic analysis (Bardin, 1977; Berelson, 1971). All transcripts were checked by the first author who conducted the interviews. These transcriptions were then read and reread to allow a deeper understanding of the data obtained, as well as subsequently facilitating their formal analysis (Howe, Worrall, & Hickson, 2008; Michallet, Tétreault, & Le Dorze, 2003). Then, a matrix of subject areas was defined based on elements that emerged from data analysis, areas identified in current literature and the objectives that had driven data collection. This matrix was composed of the following: consequences of stroke in body functions and structures; consequences of stroke in activities/participation; consequences of aphasia in body functions and structures; consequences of aphasia in activities /participation; activities no longer performed after stroke; activities usually performed after stroke; barriers encountered; facilitators encountered. After the construction of the matrix, the encoding of the data was performed (see an example in appendix 2). Individual words or phrases comprised a "registration unit of data". Units of data that were similar were then grouped together to form broader subcategories, and then categories. Frequency counts of data according to sub-category and category were additionally undertaken to identify and prioritise concepts thereby assisting with summarising the data (Krippendorff, 1988). Content analysis was also applied to SLTs' written responses, and similarly, frequency counts were also undertaken to aid summarising and synthesis of main findings. In the following Results section quotes from participants have been used to illustrate their views. For the convenience of the reader, comments have been translated from EP to British English and the "aphasic nature" of these has been maintained as much as possible. Original EP data is available from Matos (2012). All the translations were checked by the authors. The analysis itself was done on the EP data and the WHO ICF framework (WHO, 2001) was used as a structure for organising the data, as used previously in qualitative studies to frame findings (Howe et al., 2008; Kagan & Simmons-Mackie, 2007; Le Dorze & Brassard, 1995). Thus, categories were arranged according to Impairments in Body Structures and Functions and Activities Limitations/Participation Restrictions in order to reflect the consequences of stroke and aphasia. Activities/Participation categories were used to reflect functionality after stroke and aphasia. In a very small number of instances, some units of data were unable to be coded against ICF codes, so they were tagged with the label "Loss of Autonomy" (see further information in the Discussion).

An independent and experienced SLT with 20 years of experience in aphasia and good knowledge of the ICF checked the content analysis and coding for one of the three final tables of SLT group results, as well as for 10% of the FM and PWA interviews yielding 82.6% agreement with the first author on the SLT data, 78.7% on the FM interviews and 80% on the PWA interviews. Discrepancies were identified and discussed, reaching a coding consensus.

RESULTS

Impairments in Body Functions and Body Structures – People with aphasia

The majority of PWA in the study reported the effects of stroke mainly in the category of *Mental Functions*, namely in *Specific Mental Functions* and within this, in *Mental Functions of Language* and more specifically in the *Expression of Language: "I knew everything, everything. Could not speak"; "I had, I had one one (sigh) want to speak but nothing comes out"; "I knew everything, everything. But to say nothing"*. The second most referred category as being hindered with stroke, was that of *Neuromusculoskeletal and Movement-Related Functions: "It was paralysed arm"; "one one one one white, aaaarm, right now seems pa pa was also paralysed. paralysed".*

PWA interviewed individually reported more consequences than were revealed in the group interview, reported more diverse *Mental Functions* (including *Consciousness Functions* and *Calculations Functions*) and were more varied in impairments including *Sensory Functions and Pain*; *Functions of the Digestive, Metabolic and Endocrine Systems; Memory Functions; Energy and Drive Functions; and Psychomotor Functions*.

Impairments in Body Functions and Body Structures – Family members and Friends

FM were unanimous in considering the category of *Mental Functions*, namely in *Specific Mental Functions* and *Global Mental Functions* as the most affected and within this: *Mental Functions of Language: "…she no longer knows how to read..."; "Speaks much more"; "But sometimes she tries to say a particular phrase and in fact she is unable to do it. In fact she is very far from being able to say it"*; *Emotional Functions: "Cries at everything and anything"; "Pouts. My mother pouts"*; and *Energy and Drive Functions*: *"…feels more tired... there are days that he feels more or less tired..."; "Because he cannot, love. Because he cannot do it now"*. Consequences in the category of *Neuromusculoskeletal and Movement-Related Functions* were also referred to, although to a much lesser degree*: "She has some difficulty in picking up things with her right hand"; "... she has no motor capacities to grab a spoon, and let's it fall".*

Impairments in Body Functions and Body Structures – Speech and language therapists

The SLTs in this study reported consequences of stroke in the following six categories: *Mental Functions*; *Sensory Functions and Pain*; *Voice and Speech Functions*; *Functions of the Digestive, Metabolic and Endocrine Systems*; *Neuromusculoskeletal and Movement-Related Functions*; *Functions of* the *Cardiovascular, Haematological, Immunological and Respiratory Systems*.

The three SLTs groups all referred to the category of *Mental Functions*, namely *Specific Mental Functions*, and especially the subcategory of *Emotional Functions: "Depression"; "Reduced self-esteem"; "Behaviour (lability)"*. Two SLT groups referred to the consequences of stroke in *Mental Functions* of Language: "Language: aphasia, alexia, agraphia/dysgraphia") and *Higher Level Cognitive Functions*: "Reasoning". The lesser mentioned subcategories (raised by one group only) were *Attention Functions*: *"Attention", Calculation Functions: "Calculation", Memory Functions*: *"Cognitive disorders,*

memory", *Temperament and Personality Functions*: *"Psychological"*, and *Mental Function of Sequencing Complex Movements: "Apraxia*". Most of the consequences categorised under *Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems* were reported by two SLT groups, except *Breathing Functions: "Changes in respiratory control",* which was reported by only one group.

Summary

All three groups reported the *Mental Functions* as being the most affected category, namely *Specific Mental Functions* and *Global Mental Functions*. PWA and FM groups valued the *Mental Functions* of *Language* and *Energy and Drive Functions* subcategories, while the SLT group highlighted the *Emotional Functions* and the *Temperament and Personality Functions* subcategories. All groups also referred to physical consequences in *Neuromusculoskeletal and Movement-Related Functions*. FM were focused in their reporting, whilst PWA and SLT groups were more diverse. See Table 4 for an overview of *Body Functions and Body Structures* coded ICF chapters appearing across participants' data. The ICF categories are listed in the order of emphasis as present in the data, not in order of the WHO ICF classification scheme.

Activities / Participation after stroke – People with aphasia

PWA were explicitly questioned about their activities and participation in their present day experience i.e. the range of activities they were currently involved in. PWA interviewed individually reported performing activities of *Mobility*, most specifically *Walking and Moving: "I'll just walk around for an hour, an hour and such"*; activities within *Community, Social and Civic Life: "No, I'm going there, the all day.* [But where? The cafee?] *Yes"*, within *Major Life Areas: "... and grazing sheep"*; *Domestic Life*: *"And while* [gestured ironing]*, clean everything I can"* and *Communication*: *"But the the there is no one I can't talk with"*. PWA interviewed as a group mentioned carrying out activities of *Community, Social and Civic Life,* specifically *Recreation and Leisure* activities: *"Look, me for example, I'm to casino too much time*"; activities within *Major Life Areas* most specifically Work *and Employment:* "*I do doo* [gestured digging] *just do. Cut some herbs"* and *Learning and Applying Knowledge*, most specifically *Applying Knowledge*: *"So I write, during the week I write".*

Activities Limitations / Participation Restrictions – People with aphasia

PWA reported consequences in *Major Life Areas*, most specifically in *Work and Employment: "it was… not work"; "I'm in the establishment, but it is, it is almost nothing"*, and in *Community, Social and Civic Life,* most specifically *Recreation and Leisure*: *"Aaaand also liked to play, these things cannot right now"; "and at the weekend* [makes gesture of leave] *use to live with my wife, going here... and was always at ease. And not now*". PWA interviewed as a group reported consequences in *Interpersonal Interactions and Relationships*: *"There were people very good good friends, very good friends, who currently have nothing of friends"* and in *Communication*: *"I avoid talking to people because one can* [shrugs] *talk as it should be"; "I even with my children I, all all the time talking to me, but I rarely say something"*. PWA interviewed individually reported consequences in *Mobility: "it's the car* [shrugs], *that is wor, that is worst", Learning and Applying Knowledge*: *"Just wan, want to do some, some things with my hand* [gestured writing] *in order to make it in the computer,*

but I can't…" and Loss of Autonomy: *"Not alone, but alone I mean well with* [pause] *with family, my wife is doing it".*

Activities / Participation after stroke – Family members

FM reflected on activities currently undertaken by their PWA. FM reported a number of activities, reflecting what PWA can do despite the impairments, and interestingly, many of these were undertaken at home (and nearby). FM reported activities related to *Community, Social and Civic Life*, and more specifically *Recreation and Leisure* activities: "*watching TV" and "going to watch the soccer"* as being the most performed by PWA after stroke. Both groups also referred to *Self-care: "will shave himself"*, *Mobility: "take a walk up the street"*, *Communication: "He is contacted by telephone or any talk of him"*, *Major Life Areas* activities, including *Work and Employment*: "He became a farmer. Orchard", *Domestic Life*: *"Yes, he always do his bed, he never forgets to do it, to do his bed"* and *Learning and Applying Knowledge: "He's always studying, always. Reads a lot*". Only FM interviewed in group referred activities related with *General Tasks and Demands*: *"He is very, very organised. We get home and his papers, all his documents are there".* Although FM reported PWA engaging in activities pertaining to *Work and Employment*, FM mentioned restrictions, namely: one PWA was working half days; one PWA was supported in the family shop; one PWA worked in agriculture (grew his own fruit and vegetables).

Activities Limitations / Participation Restrictions – Family members

Family members interviewed in group, reported consequences in *Mobility: "the biggest difficulty is mobility, no doubt, at this time"; "The first, the biggest difficulty that he has is not being able to drive"*; *Community, Social and Civic Life: "From there, we stopped strolling, we stopped doing"; "Not alone, no, alone he does not leave the house"*, and Loss of Autonomy categories. *Domestic Life* consequences were also referred to: *"he has difficulty cutting the bread, I do it instead"*. FM interviewed individually additionally reported consequences relating to *Self-Care:* "*wash and dry up", "taking care of the body and body parts", "getting dressed", "eating and drinking" and "take care of own health*", *Communication: "Okay, now we cannot have a conversation thus very… Chatting up a few things but it is so banal, almost"; "We talk much less than we used to, we used to talk a lot, and discuss a lot*", *Major Life Areas: "Stopped working, stopped working"; "We have no money, we have less money, isn't it? And we have to make a balanced life. We cannot spend too much*", *Interpersonal Interactions and Relationships*: *"he liked to play with the kids in a way that does not play now…*" and *Community, Social and Civic Life: "…he is not going to the mass…"* and in fact, FM valued these more than the above-mentioned categories, as those which are most affected by stroke.

Activities / Participation after stroke – Speech and language therapists

SLTs reported a range of current activities for PWA in three categories, namely in *Community, Social and Civic Life*, more specifically in *Recreation and Leisure*: *"Go to the supermarket near home"*; *Domestic Life*: *"stay at home", "stay in bed"* and *Self Care* specifically *Looking after one's health*: *"Going to the hospital for treatment" or "Going to speech therapy"*. SLTs described PWA as more passive now in some of their activities, having restricted roles (unspecified), and activities would likely be limited to those undertaken with close family or within a family context.

Activities Limitation / Participation Restrictions – Speech and language therapists

SLTs reported many consequences, and more than were categorised in *Body Functions and Body Structures*. SLTs also described a range of consequences with great variety amongst their responses. The domain primarily affected was *Interpersonal Interactions and Relationships: "Isolation and personal or family"*. However SLTs also reported consequences affecting *Community, Social and Civic Life*: *"Go out with friends"*, *Major Life Areas*: *"Changes in lifestyle* [social]" and "*Loss or modification of the employment situation*", with many consequences in terms of *Work and Employment*: *"Stop work"* and their impact on *Economic Life*: *"Dealing with issues in finance, in the mail*" and *Communication*: "*nonverbal communication" and "changing the communicative profile".* Within *Community, Social and Civic Life, Recreation and Leisure* was the most affected: *"Decreased participation in social activities, leisure". General Tasks and Demands*: *"reduced general functional independency*", *Mobility*: *"driving"* and *Self-Care: "changes in life style* [*food,...*]*"* were also referred but were not as valued as the other described categories.

Summary

A broad range of Activity/Participation domains reflected the impact of stroke and aphasia and the current life experience of PWA (see Table 5). Whilst there was commonality amongst all groups, as well as between two groups only, there was evident diversity in the views and emphases of PWA, FM and SLTs. The most common finding was the emphasis on *Community, Social and Civic Life*, namely in *Recreation and Leisure* as both substantially affected, but also a current life experience. *Major Life Areas*, namely *Work and Employment*, *Communication*, *Interpersonal Interactions and Relationships and Mobility* were also common to all three groups. According to these, PWA engaged in several activities related with *Community, Social and Civic Life, Domestic Life* and *Self-Care*. It is evident that stroke and aphasia impacted the FMs' activities and participation, as jointly undertaken activities were affected.

DISCUSSION

The findings from this study, albeit small and focused in one geographical area of Portugal, suggest that the experiences of Portuguese people with aphasia are similar to those reported in other countries (Alguren et al., 2010; Darrigrand et al., 2011; Mazaux et al., 2013; Natterlund, 2010; Paanalahti et al., 2013; Zemva, 1999).

Impairments in Body Functions and Body Structures

Stroke and aphasia clearly impacted on language, physical ability and emotions, confirming findings of existing literature. Difficulties with speaking, reading and writing have been often reported (Darrigrand et al., 2011; Le Dorze & Brassard, 1995; Zemva, 1999). Changes in mood and emotional reactions have also been previously reported (LeDorze & Brassard, 1995; Zemva, 1999) and broader literature on emotions (Martins, 2006; Santos, Farrajota, Castro-Caldas, & Sousa, 1999; Sutcliffe & Lincoln, 1998) reinforces the need to consider emotional disorders and more specifically depression

as a consequence of stroke. In Portugal, psychologists are not frequently employed in stroke teams and the SLT may have an important role in identifying patients and referring for support for emotional needs and disorders. The results obtained may be an alert to the growing need for psychologists to be integrated in services and teams directly involved with these situations. The current study confirms existing literature on physical sequelae of stroke (Le Dorze & Brassard, 1995; Natterlund, 2010; Parr, 1994; Zemva, 1999), which has been previously recognised as impacting on social and life activities (Natterlund, 2010) and life satisfaction (Parr, 1994). Framing the impairment consequences using the ICF revealed a diverse impact of stroke and aphasia across six categories: *Mental Functions; Neuromusculoskeletal and Movement-Related Functions; Sensory Functions and Pain; Functions of the Digestive, Metabolic and Endocrine Systems; Voice and Speech Functions; Cardiovascular, Haematological, Immunological and Respiratory Systems*. The current findings confirm that *Mental Functions and Neuromusculoskeletal and Movement-Related Functions* are most affected at 3 months post-stroke (Alguren et al., 2010) and at chronic stages (Paanalahti et al., 2013). Similar to Paanalahti et al. (2013) the consequences are reported to be more diverse in the chronic period.

All three groups reported consequences primarily in *Mental Functions (Specific Mental Functions and Global Mental Functions)* and *Neuromusculoskeletal and Movement-Related Functions.* As anticipated, differences were found amongst stakeholders' views. Some consequences were shared only between PWA and SLTs (*Sensory Functions and Pain,* and *Functions of the Digestive, Metabolic and Endocrine Systems*), and others were specific to SLTs alone (*Voice and Speech Functions,* and *Cardiovascular, Haematological, Immunological and Respiratory Systems*). Overall, FM were focused in their reporting, and PWA and SLTs groups were more diverse. PWA reported more language/communication difficulties, whereas FM and professionals reported more emotional consequences. This finding was similar to the emphasis identified by Zemva (1999) between aphasic individuals and family members; however professionals' emphasis on emotional consequences warrants further consideration. It is possible that the SLTs did not feel it was necessary to report language consequences (taking these for granted within the study), and instead emphasised emotional consequences as more important. Finally, PWA interviewed *individually* reported more varied and severe consequences, than those interviewed in a *group*. These findings may have occurred for various reasons. It may be due to participant subsample differences, i.e., those interviewed individually presented with more serious linguistic disturbances and with more impairments to describe. Alternatively, individual interviews may suggest a larger availability and attention on the part of the interviewer, which can also function as facilitator of the communication process. Finally, it also may be that the group setting was a barrier in not enabling individuals' opinions to be heard, as suggested previously by Howe et al. (2004).

Activities Limitations / Participation Restrictions

The areas of work and employment, recreation and leisure, interactions and relationships, communication and mobility were most frequently reported as limited and restricted post stroke with aphasia. These findings are in agreement with the existing literature (Dalemans, De Witte, Wade, & Van den Heuvel, 2008; Daniel, Wolfe, Busch, & McKevitt, 2009; Michallet et al., 2003; Natterlund, 2010; Parr, Byng, Gilpin, & Ireland,

1997). Whilst all stakeholders considered these five areas were considered as affected, each group placed different emphases on each area. Work and employment is universally restricted with aphasia (Code, 2003; Dalemans et al., 2008; Daniel et al., 2009; Michallet et al., 2003; Natterlund, 2010; Parr et al., 1997), and only one individual (10%) in the current study was working at the time of the interview, in the same job but part-time with reduced activities and different functions, similar to experiences described by Dalemans et al. (2008). Moreover, in Portugal, whilst there are work integration policies in principle, as well as financial incentives for the integration of people with disabilities (MSSS, 2012), in practice, resources are scarce, especially for people with neurological disorders, which may further complicate and hinder employment for people with aphasia.

Leisure and recreation activities are often described as the most disturbed activities after stroke and aphasia (Dalemans et al., 2008; Hinckley, 2002; Le Dorze & Brassard, 1995; Parr, 2001), both in terms of affected social activities and contacts, as well as interactions and social relationships. All participants reported restricted activities, which have important implications for stroke and aphasia long-term recovery given the role of social engagement in healthy living and wellbeing (Cruice et al., 2003). Interestingly, professionals emphasized impact on interactions and relationships, more than individuals with aphasia and family members did, which may be related to the association of communication and interaction, and this being a common goal in therapy. Whilst restricted communication is an unsurprising finding in the data, it appears as third to sixth priority (see Table 5) possibly suggesting the impact of aphasia is felt more keenly on broad life areas first than on specific fields of speaking, reading and so forth. Alternatively, it may be that the cumulative impact of physical, language and emotional difficulties are more noticeable in their combined impact on life purposes, hence these are discussed before the language impairment. Although not explicitly within the remit of a speech and language therapist, mobility is important for providing access to social opportunities. In this study, mobility difficulties clearly limited people's activities and lives, and are similar to those issues previously reported affecting life engagement both within and outside the home (Code, 2003; Natterlund, 2010). More than half of the PWA involved in this study presented a right hemiparesis, giving rise to these findings.

Framing the Activities/Participation consequences using the ICF revealed a diverse impact of stroke and aphasia that spanned all nine domains, and aligns with research undertaken with Swedish community-living stroke survivors that asserts the relevance of all domains in a comprehensive core set (Paanalahti et al., 2013). Interestingly, domains reported to be most affected in Paanalahti's (2013) sample in order of emphasis - *Mobility, Self-care*, *Domestic Life, Interpersonal Interactions and Relationships*, *General Tasks and Demands, Communication* – are quite different to the current study's findings where much greater emphasis was placed on *Major Life Areas*, *Community, Social and Civic Life,* and *Communication*. The differing emphasis on *Communication* can be explained by the small number of aphasic participants (N=2 in Paanalahti et al. (2013)); explanations for the other differences are less clear and may be attributed to participant sample differences such as chronicity.

All three groups reported Activities and Participation limitations and restrictions in the same five domains outlined at the start of this section, albeit with different emphases.

Several findings are worthy of some discussion. Recreation and leisure was considered similarly important to all groups; work and employment was more important to people with aphasia and professionals, than to family members; family members emphasized aspects relevant to instrumental activities of daily living – mobility, domestic life and self-care; and finally, family members and to some extent people with aphasia also, reported a loss of autonomy in daily living. It is probably that family members cohabiting with the person with aphasia are privy to the daily challenges experienced within the home, and also likely to have caregiving responsibilities (Grawburg et al. 2013) subsequent to their partners' stroke. It is possible that family members' reporting of these needs reflect gaps in service provision in Portugal for long-term home support for people with stroke and aphasia. Although family members in this study were asked to report on their relative with aphasia, it was clear from their responses that stroke and aphasia also impacted on their *own* activities and participation. Finally, one of the small yet important findings of this study is the reporting of autonomy. This finding is unsurprising given the situation people and families find themselves in post-stroke, and it has been previously identified (Le Dorze & Brassard, 1995; Zemva, 1999), and is not to be confused with independence which is better represented in the ICF. Autonomy may relate more to being, rather than doing, and deserves more attention in consequences-focused research.

Activities / Participation after stroke

Thus far, the limitations and restrictions have been discussed, however people with aphasia and family members also reported many experiences of continuing to engage and participate in activities. It is possible that participants wanted to reflect a balanced view of their lives, and focus on competency and engagement in spite of the circumstances. All stakeholders reported experiences of PWA engaging and participating in *Community, Social and Civic Life* (Recreation and Leisure), *Domestic Life,* and *Self-Care*, however again with varying emphases, and notably this engagement was still described as affected by stroke and aphasia. For example, activities were limited to a familiar context or nearby people's homes, which is similar to other studies' findings (Cruice, Worrall, & Hickson, 2006; Davidson, Worrall, & Hickson, 2003).

Two reflections specific to professionals' contributions are worthy of some discussion. SLTs described more consequences of stroke and aphasia related with the Activities/Participation domains then they did in terms of Body Functions and Body Structures. This suggests that Portuguese SLTs are concerned about the broader impact, and represents a shift away from the medical model, which is dominant in Portuguese practice. Whilst SLTs proposed many possible limitations and restrictions, they were less clear about potential continued participation, suggesting only activities relating to caring for oneself, being in the home, and socialising. It is possible that one can over-estimate the impact of stroke and aphasia on daily living, and need the lied experience to more fully identify what is possible despite stroke and aphasia.

Clinical implications

According to this study, the impact of stroke and aphasia on functioning, activities and participation is perceived to be diverse by those who have and live with the condition,

and those who work with PWA. This documentation of day-to-day consequences of stroke and aphasia suggests the need to focus on not only the person with aphasia views and wishes but also their family's opinions and needs, in order to better understand the whole process and help them to define the best goals for therapy. Some respondents were quite new to the experience of living with stroke and aphasia, whilst others had been living with the condition for some years. The findings suggest a range of unmet needs that could potentially be responsive to some form of multidisciplinary intervention, in the more chronic stage. As stroke clinical guidelines in some countries (e.g., Royal College of Physicians 2012 National Stroke Guidelines in the United Kingdom) suggest, allied health professionals and other health or social care workers and volunteers may have a greater role in longer-term management than previously appreciated. Furthermore, therapy studies with chronically aphasic participants show positive results (for example Mumby & Whitworth, 2012). Such suggestions have obvious resource implications, which are likely to be clear barriers to such service improvements, but need serious consideration internationally.

These results also provide strong evidence for the need of SLTs to consider and explore all the ICF domains. Clinicians need tools that explore the whole person's situation, such as the Assessment for Living with Aphasia (Simmons-Mackie et al., 2014), however it is clear that this assessment does not explore non-aphasia aspects and does not incorporate the family members' views. It could be that broad quality of life assessments, such as the Burden of Stroke Scale (Doyle, McNeil, Hula, & Mikolic, 2003) would reveal the range of consequences and experiences, although this may need supplementing to explore activities that people continue to do and may likely be best undertaken with a broader allied health professional team. The findings also demonstrate the value of SLT- aided discussion with PWA and FM, revealing a breadth of experiences and concerns, which can inform multidisciplinary rehabilitation. Thus SLTs may facilitate this early in rehabilitation, and then team, client and family agree who needs to be involved and what undertaken.

In Portugal, these results may have stronger implications for in SLT practices. According to Leal (2009), despite the demonstrated will in changing their practices to a more social model of intervention, many SLTs still focus their therapy in the aphasic person's linguistic impairments and activity limitations, and do not consider family members directly in therapy. Available assessment tools are focused on linguistic disorders (Leal, 2009). These findings suggest a need to either develop sophisticated case history taking practices in order to elicit the real world experience from both PWA and FM, and/or develop EP translations of existing assessments of activity and participation (Matos et al., 2010a, 2010b) to enable standardised consideration of these in therapy. The use of group therapy, not very common in Portugal, as a tool for facilitating family member inclusion in the therapeutic process, as well as to achieve a diversity of goals for people with aphasia (Sherratt et al. 2011), should be implemented more frequently. It is clear that a broader multidisciplinary team may be required to assist people with aphasia and families to live more successfully in the longer-term.

Study Limitations

The small number of participants of each included group limits the generalisation of results to Portuguese population with aphasia. Larger participant samples of all groups, reflecting greater geographical distribution across Portugal (specifically people with aphasia and family members) would enable firmer conclusions to be made regarding Portuguese people's stroke and aphasia experience. With regard to the patients involved in the study, the diversity of inclusion criteria established may also have affected the analysis of the data. No comment can be firmly made about attribution of consequences to variables such as age, severity, impairments, and this would need much larger participant samples, as would consideration of functioning with respect to individuals' environmental and personal context. Group data collection instead of individual interviews with SLTs was not ideal and might have influenced with data collected, resulting in possibly more homogeneous opinions. The same methodology across all 3 stakeholder groups would have been preferable. The use of an observational study as suggested in other studies (Howe et al., 2008) could have enriched our data findings and conclusions.

Future Directions

Firstly, future research needs to explore the mechanisms that result in altered activities and participation for people with aphasia, studying person-specific variables (aphasia severity, time post onset, associated physical disabilities) more, and also identify from those who live with aphasia what enables them and what strategies they have developed to live with their condition. Secondly, although the qualitative interviews with people with aphasia were informative, they were challenging and time consuming, and more time efficient methods for data collection are needed, specifically the development and validation of more assessments of activity, participation and the environment. Thirdly, there is a small growing body of evidence in the impact of stroke and aphasia on family members, and this needs continued investigation. Ultimately, the findings point to the need for the development and evaluation of community-based interventions that can address the needs of people with aphasia and family members and enable better quality of life for the family as a whole.

Finally, Portuguese people with aphasia, as well as their family members, are not used to being directly involved and consulted for their views in research. Methods to ensure respondents' active participation and critical analysis are needed. Both of these issues could be addressed by using a "Participatory design approach" as suggested by Galliers et al. (2012). This approach advocates involving people with aphasia as consultants in projects, empowering their individual contributions, facilitating their communication and participation in the face of impaired language skills (Galliers et al., 2012).

CONCLUSIONS

People with aphasia, family members and speech and language therapists reported a considerable range of stroke and aphasia consequences in the daily life of those who live with it. Language, physical, and emotional changes, and impact on communication, mobility, self-care, relationships, leisure and work were identified, suggesting the need of Portuguese speech and language therapists to consider and explore all the domains

suggested by the ICF in their clinical practice with people with aphasia. This will imply the use of different therapeutic approaches and consequently the use of different assessment tools and measures.

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Table 1. Demographic, aphasia, cognitive and emotional status for participants with aphasia (N = 14).

Participant Number	Gender	Age	Years of schooling	Previous Occupation	Months post stroke	Aphasia Type	LMMSE	CES-D
1	M	66	4	mechanic	89	Transcortical Motor	28	5
2	M	69	4	motorist	51	Global	23	11
3	F	72	4	domestic	3	Transcortical Sensory	23	20
4	M	67	4	merchant	24	Anomic	27	6
5	F	57	4	merchant	51	Broca	25	2
6	M	66	12	lieutenant colonel	3	Anomic	26	10
7	M	58	5	motorist	3	Anomic	29	14
8	M	80	3	factory worker	10	Anomic	22	5
9	M	73	4	farmer	17	Transcortical Motor	26	6
10	M	72	4	cafe restaurant manager	50	Transcortical Motor	28	17
11	M	41	20	civil engineer	39	Anomic	30	10
12	M	45	10	salesman	6	Anomic	30	11
13	M	72	9	business man	29	Conduction	27	4
14	F	74	15	librarian	11	Anomic	30	5

Table 2. Demographic, cognitive and emotional status for family members and friends (N = 14).

Participant Number	Gender	Age	Years of schooling	Occupation	MMSE	CES-D
1	F	63	4	Mechanic	30	16
2	F	41	6	Domestic/ seamstress	29	10
3	M	49	11	Unemployed	30	13
4	F	65	4	Merchant	28	4
5	M	64	6	Insurance professional	29	2
6	F	61	16	Secondary school teacher	29	14
7	F	33	6	Factory worker	30	5
8	F	55	4	Merchant	29	0
9	M	69	4	Domestic	26	8
10	F	64	4	Domestic	29	13
11	M	70	4	Factory worker	30	2
12	F	37	11	Unemployed	29	4
13	M	66	12	Bank employee	30	17
14	F	60	13	School teacher	30	10

Table 3. Demographic and work history information for speech and language therapists (N = 10).

Participant number	Gender	Age (years)	Degree	Experience with aphasia (years)	Workplace	English proficiency *
1	F	27	B.Sc.	3	National Aphasic Association	3/2/1
2	F	28	B.Sc.	5	Health Centre	4/3/3
3	M	52	B.Sc.	31	Hospital	3/2/1
4	F	43	B.Sc.	21	Hospital	3/3/4
5	F	32	B.Sc.	11	Hospital	1/1/1
6	M	43	M.Sc.	16	Hospital	4/3/3
7	F	25	B.Sc.	4	Rehabilitation Centre	4/2/3
8	F	30	B.Sc.	7	Hospital	3/2/2
9	F	27	M.Sc.	4	Health School/Private practice	4/3/4
10	F	42	M.Sc.	22	University/Private Practice	4/3/3

*Reading/Writing/Conversation in a 1-5 scale (self-evaluation).

Table 4. Body functions and body structures coded ICF categories.

PWA (N=14)	FM (N=14)	SLTs (N=10)
Mental Functions (b110-b199): Specific Mental Functions (b140-b189) - Mental Functions of Language (b167) - Expression of Language (b1671) - Memory Functions (b144) - Calculation Functions (b172) - Psychomotor Functions (b147) **Mental Functions (b140-b189): Global Mental Functions (b110-b139)** - Consciousness Functions (b110) - Energy and Drive Functions (b130) **Neuromusculoskeletal and Movement-Related Functions (b710-b799)** **Sensory Functions and Pain (b210-b299)** **Functions of the Digestive, Metabolic and Endocrine Systems (b510-b599)**	**Mental Functions (b110-b199): Specific Mental Functions (b140-b189)** - Mental Functions of Language (b167) - Emotional Functions (b152) **Mental Functions (b140-b189): Global Mental Functions (b110-b139)** - Energy and Drive Functions (b130) **Neuromusculoskeletal and Movement-Related Functions (b710-b799)**	**Mental Functions (b110-b199): Specific Mental Functions (b140-b189)** - Emotional Functions (b152) - Mental Functions of Language (b167) - Higher Level Cognitive Functions (b164) - Attention Functions (b140) - Memory Functions (b144) - Calculation Functions (b172) - Mental Function of the Sequencing Complex Movements (b176) **Mental Functions (b140-b189): Global Mental Functions (b110-b139)** - Temperament and Personality Functions (b126) **Sensory Functions and Pain (b210-b299)** **Voice and Speech Functions (b310-b399)** **Functions of the Digestive, Metabolic and Endocrine Systems (b510-b599)** **Neuromusculoskeletal and Movement-Related Functions (b710-b799)** **Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems (b410-b499)**

Table 5. Activities/ Participation coded ICF chapters.

PWA (N=14)	FM (N=14)	SLTs (N=10)
Activity Limitation/Participation Restriction		
Major Life Areas (d810-d899) - Work and Employment (d840-d859) **Community, Social and Civic Life (d910-d999)** - Recreation and Leisure (d920) **Communication (d310-d399)** **Learning and Applying Knowledge (d110-d199)** **Interpersonal Interactions and Relationships (d710-d799)** **Mobility (d410-d499)** - Walking and Moving (d450-d469) **Loss of Autonomy** (not in the ICF) **Domestic Life (d610-d699)**	**Community, Social and Civic Life (d910-d999)** - Recreation and Leisure (d920) **Mobility (d410-d499)** **Loss of Autonomy** (not in the ICF) **Domestic Life (d610-d699)** **Self-Care (d510-d599)** **Communication (d310-d399)** **Major Life Areas (d810-d899)** - Work and Employment (d840-d859) - Economic Life (d860-d879) **Interpersonal Interactions and Relationships (d710-d799)**	**Interpersonal Interactions and Relationships (d710-d799)** **Community, Social and Civic Life (d910-d999)** - Recreation and Leisure (d920) **Major Life Areas (d810-d899)** - Work and Employment (d840-d859) - Economic Life (d860-d879) **Communication (d310-d399)** **General Tasks and Demands (d210-d299)** **Mobility (d410-d499)** **Self-Care (d510-d599)**
Engagement in life after stroke and aphasia		
Community, Social and Civic Life (d910-d999) **-** Recreation and Leisure (d920) **Major Life Areas (d810-d899)** -Work and Employment (d840-d859) **Domestic Life (d610-d699)** **Learning and Applying Knowledge (d110-d199)** **Mobility (d410-d499)** -Walking and Moving (d450-d469) **Communication (d310-d399)** **Self-Care (d510-d599)**	**Community, Social and Civic Life (d910-d999)** **-** Recreation and Leisure (d920) **Self-Care (d510-d599)** **Mobility (d410-d499)** **Communication (d310-d399)** **Major Life Areas (d810-d899)** -Work and Employment (d840-d859) **Domestic Life (d610-d699)** **Learning and Applying Knowledge (d110-d199)** **General Tasks and Demands (d210-d299)**	**Community, Social and Civic Life (d910-d999)** **-** Recreation and Leisure (d920) **Domestic Life (d610-d699)** **Self-Care (d510-d599)**